

## **PART II**

### **GENERAL APPLICATION REQUIREMENTS**

#### **LEAD AGENCY**

Governor John Waihee designated the Department of Health as the Lead Agency for Part H of P.L. 99-457 (now Part C of P.L. 105-17) on May 14, 1987. This responsibility was reiterated when Governor Waihee signed H.B. 845 into law as Act 107-89 on May 31, 1989, delegating administrative, rulemaking, and monitoring responsibility to the Department of Health for the establishment of a statewide, comprehensive, coordinated, multidisciplinary program of early intervention services for infants and toddlers with special needs and their families. This policy is contained in HRS §321.351, a copy of which is included in the Appendix. The Department assures that all new requirements required by P.L. 105-17 are in place.

Within the Department of Health, the program is under the supervision of the Deputy Director for Health Resources Administration. The Division of Family Health Services was assigned responsibility within the administration for the management of the Zero-to-Three Hawaii Project to implement Part H for the State of Hawaii. For the first eight years of the project, it was under the oversight of the Chief of the Children with Special Health Needs Branch. The fiscal management for the project was contracted through the Research Corporation of the University of Hawaii for the first nine years.

A reorganization has been approved that creates the Zero-to-Three Services Section. The Department has now assumed all organizational responsibility for the program. Copies of the current organizational charts for the Department, Division, Branch, and Zero-to-Three Services Section are included in the Appendix.

#### **HAWAII EARLY INTERVENTION COORDINATING COUNCIL**

**Composition.** The Governor appointed members of the Hawaii Early Intervention Coordinating Council (HEICC) for staggered one, two and three year terms, effective July 1, 1987. Reappointments and new appointments have maintained a Council of 15 members that is consistent with the requirements of

P.L. 105-17 (Paragraph 303.141). The composition of the Council also meets the requirements of HRS §321.353, which sets the number of members at 15. Additional members serve in an ex-officio capacity.

Three of the 15 (20%) are parents of children with disabilities under the age of six. Additionally three other Council members have older children with disabilities. Three members represent providers. There is a representative from the state Legislature and from the University of Hawaii (personnel preparation). All agencies paying for services are represented and are at a policy decision-making level of authority. The Director of Special Education is a member. There is also a representative from the agency governing public health insurance.

All ethnicities in Hawaii are minorities. Among parent membership, the Hawaiian, Pacific Islander, Japanese, Black American and Caucasian ethnicities are represented. All of the parents have children with special needs under the age of six. The Chairperson is a parent member. The Chairperson is not and has never been a representative or employee of the Department of Health (lead agency).

A full listing of the Council membership is included in the Appendix. The Chairperson of the Council is elected by the Council. No representative from the lead agency is eligible for election. The other elected officer is a Vice-Chairperson. By-Laws have been officially adopted which are consistent with P.L. 105-17. The Council establishes committees, as necessary, to assist it in its responsibilities. A copy of the By-Laws is included in the Appendix.

There is an Executive Committee which consists of seven members, including the officers and the chairpersons of each committee. The Executive Committee also serves as the Committee on Legislation.

**Meetings.** Meetings of the HEICC are held quarterly, usually on the fourth Wednesday of the month. All meetings are open, with a published Agenda and previous minutes on public display one week prior to the date of the meeting. Likewise, the monthly meetings of the Executive Committee are also open meetings. Interpreters and other necessary services will be provided for persons who require these services, whether it is a Council member or a visitor in the audience.

**Conflict of Interest.** No member of the Council may cast a vote on any matter that would provide direct financial benefit to that member or otherwise give the appearance of a conflict of interest.

**Functions of the HEICC.** The Council functions in a manner consistent with the Congressional intent as outlined in P.L. 105-17, as well as State legislative intent as described in HRS §321.353. The Council advises the Director of Health on issues relative to the planning, implementation, evaluation and monitoring of the statewide system of early intervention services.

The Council assists the lead agency in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the State. It assists the lead agency in the effective implementation of the statewide system. The Council seeks information from services providers, care coordinators, parents, and others about any Federal, State, or local policies that impede timely service delivery. If problems are identified, it seeks to assure that they are appropriately referred and resolved. As disputes arise, the Council will assist the lead agency in the resolution of disputes.

This process usually consists of staff work which is presented to one of the Committees of the Council, providing background information. The appropriate committee then discusses, does further research, conducts other investigative activities, eventually making recommendations for implementation. These recommendations are then generally summarized in an overall "Position Paper" on the subject that is forwarded to the Executive Committee for review. Upon their approval, the recommendations are forwarded to the full Council. Following their deliberations, the recommendations are then forwarded to the Director of Health. The Director of Health has thus far accepted all the programmatic recommendations for implementation.

The Zero-to-Three Services Section staff are responsible for the implementation of these approved recommendations. This process has been successfully followed for developing the definitions of the population, for the implementation of the IFSP, and for the development of the central directory of services, among others.

The Council also has advised and assisted the Department, not only in the annual application for continued Part C funding, but for a number of other grants that have been prepared to obtain further resources to address the needs of this population. This has included grants under the Children's Justice and Assistance Act, for funding crisis nurseries and respite care services. It has also included a Healthy Tomorrows Grant, in partnership with the American Academy of Pediatrics and the Bureau of Maternal and Child Health. The Council was also supportive in obtaining various grants from the U.S. Department of Education and the Department of Health and Human Services.

During recent years, several feasibility studies have been funded under the U.S. Department of Education. There is currently a Child Find Evaluation study underway. A model demonstration project, in collaboration with the Hawaii University Affiliated Program has just been funded to develop innovative approaches to improve child find activities. Additionally, a grant is being administered from the Centers for Disease Control for a longitudinal research study on the impact of high quality, intensive early intervention services for infants whose mothers have less than a high school education.

The Department currently has a grant funded from the Department of Human Services (DHS), using Child Care and Development Block Grant (CCDBG) funds, to develop inclusion services for infants and toddlers with disabilities. This grant is intended as a model demonstration project to both enhance the community's capacity to serve children with special needs as well as to direct a share of the resources of the CCDBG funds to provide child care services to meet the needs of families with young children with disabilities. This is a collaborative project between the two agencies.

The Department also has received a five year model demonstration grant to develop supportive parenting services for the parents of children under Part C who are themselves cognitively disabled.

The Council also advises and assists the Director of Health in the identification of the sources of fiscal and other support for services for early intervention programs. Most recently this has included recommendations for a carve-out under Medicaid and efforts to access CHAMPUS funding.

These efforts have also included recommendations for amending the State Medicaid Plan to include targeted case management services for infants and toddlers with special needs and in developing an amendment to include a special benefit for early intervention services.

The Council will assist the Department in the areas of assignment of financial responsibility and the promotion of interagency agreements. The Council has been directly involved in all the recommendations for direct service grants. The Executive Committee reviews all proposals, then submits the recommendations for funding to the full Council. Following its deliberations, the HEICC then recommends to the Director of Health those projects which should be funded. The Director has always concurred with recommendations of the Council.

The Council will also advise and assist the Department of Education to support the transition of toddlers with disabilities to services provided under Part B, to the extent those services are appropriate. The Council may also advise the lead agency and the State Education Agency (SEA) regarding appropriate services for children from birth to age five.

Most recently the Council has succeeded in legislative efforts to mandate the provision of early intervention services by private health insurance plans.

A Report on "Early Intervention for Infants and Toddlers with Special Needs and Their Families" has been prepared for each year since the Council was

established. Each annual report contains information required by the Secretary for the reporting year. This report is intended to not only report to the Secretary and the Governor, but to serve as a primary vehicle for public awareness and education of policymakers. The report concentrates on what has been accomplished over the previous year, as well as plans for the future. A copy of the most recent report is included in the Appendix.

As an example of the close advisory relationship between the HEICC and the Department, all policy memorandum issued to update the State Plan are countersigned by both the Director of the Department and the Chairperson of the HEICC.

The Council has developed a vision of the overall statewide system of services. This vision has enabled it to take the work of all its various committees, to fit those recommendations into a unified whole to assure a unified statewide system. This vision of the statewide system to meet the needs of all infants and toddlers with special needs and their families is shown on the following page.

## PLANNED USE FOR FY 1998 FUNDS

### Description of Use of Funds

**Personnel.** The personnel outlined in the budget will provide either administrative or technical support to the statewide system of services, or provide direct services to infants and toddlers. Some of these position titles have changed because of the transfer of the fiscal management of the project from the Research Corporation of the University of Hawaii to the Department of Health. However, the functions and job descriptions have remained unchanged. All positions are full time, except the ones so indicated. Federal funds are used to pay 100% of the salaries, except for the ones at .75 FTE. For those two positions, federal funds are used pay the .75 FTE, or 75% of a full-time salary.

**Public Health Supervisor VI.** This person is assigned responsibility for the overall planning, implementation, and supervision of the Part C system and for providing liaison with the Hawaii Early Intervention Coordinating Council.

**Child & Youth Specialist V.** This individual supervises the child find system, the private contracts and purchase-of-service contracts, the central directory of services, data collection, and a number of statewide resource people and direct service providers.

**Child & Youth Specialist IV (Third-Parry).** This person is responsible for overseeing all third-party billing efforts, including the early intervention carve-out and Title IV-E reimbursements.

**Child & Youth Specialist IV (Training).** This person is responsible for assessing training needs and for coordinating the delivery of needed training.

**Child & Youth Specialist IV (H-KISS).** This person is directly responsible for the supervision of the central directory of services, the central point-of-contact, and the data tracking systems.

**Child & Youth Specialist IV (HEICC).** This person is responsible for providing support for the HEICC, compiling their annual report, and providing other needed public awareness activities.

**Accountant III.** This person provides fiscal support for the early intervention system of services.

**Information Specialist III.** This person is responsible for overseeing child-find activities.

**Special Education Teacher IV (Inclusion).** This individual provides support for all care coordinators and families to encourage the provision of services in natural environments.

**Special Education Teacher IV (Assistive Technology) (.75 FTE).** This person provides support to programs in training, planning, developing, and adapting assistive technology to meet the needs of individual children.

**Occupational Therapist III.** This person provides occupational therapy consultation to programs and support and services for infants and toddlers natural environments.

**Special Education Teacher III.** This person provides special instruction consultation to programs and support and services for infants and toddlers in natural environments.

**Social Worker III.** This person provides care coordination and social work support and services for infants and toddlers in natural environments.

**Physical Therapist III.** This person provides physical therapy consultation to programs and support and services for infants and toddlers in natural environments.

**Speech-Language Pathologist III.** This person provides speech-language consultation to programs and support and services for infants and toddlers in natural environments.

**Social Services Assistant V.** This person oversees the arrangements for the authorization for services and coordinates respite services for infants and toddlers in the system.

**Data-Processing System Analyst III (.75 FTE).** This individual provides training and support for all the computer technology and the data management systems, including the third-party billing systems.

**Social Worker II (2 - 1.FTE).** These two individuals provide referral services and information counseling to individuals calling the central directory of services. They assign an interim care coordinator at the central point-of-contact, and provide data entry for portions of the data management system.

**Educational Assistant III.** This person provides training, adaptations, and support for parents and families as they utilize assistive technology with their infants and toddlers in the home.

**Account Clerk II.** This person provides accounting support for the processing of payments for services and for personnel actions.

**Secretary II.** This individual provides secretarial support for the entire statewide administrative structure.

**Fringe Benefits.** Fringe benefits are calculated at the official state rate of .3697 of total salaries.

**Equipment.** Funds are budgeted for the replacement of obsolete computer or other equipment.

**Supplies.** Minimal funds are budgeted for the purchase of office and program supplies.

**Travel.** Funds are budgeted for local mileage reimbursement for staff, for interisland travel for training and monitoring purposes, and for mainland travel to national meetings of critical programmatic importance to the early intervention system.

**Consultants.** Funds are budgeted for two consultants for the next fiscal year. One consultant would assist with establishing unit costs for services to support the early intervention carve-out. Another consultant is needed to assist with the utilization of the Early Intervention Trust Fund and to develop a viable carve-out proposal for services for preschool children between ages three and five who are not eligible under Part B.

**Publications.** Funds are included to purchase essential publications to keep staff members knowledgeable about early intervention issues.

**Other.** Funds are budgeted for partial payment of the telephone service, for the lease of office space, and for purchase-of-service contracts for providers of early intervention services.

**Hawaii Early Intervention Coordinating Council.** Funds are included to support parents' participation in the activities of the Council, for the HEICC Chair to attend the national Part H meeting, and for publication of the annual report.



## ***Budget for Year XII***

Personnel .....	682,620
Fringe .3697 .....	252,365
(state rate of .3697)	
Equipment .....	5,000
Supplies .....	14,000
Travel .....	27,253
Mileage .....	5,000
Interisland .....	10,000
Mainland .....	22,000
Consultants .....	20,000
Publications .....	5,000
Other .....	700,421
Telephone .....	13,410
Lease .....	138,239
Purchase-of-Service Contracts .....	548,772
Hawaii Early Intervention Coordinating Council .....	7,000
Parent Stipends/interisland travel .....	1,500
Chair travel to national meeting .....	2,000
Annual Report .....	3,500
<b>TOTAL YEAR XII FEDERAL PART C BUDGET.....</b>	<b>\$1,713,659</b>

## ***ADOPTION OF STATE POLICY ON STATEWIDE SYSTEM***

The State of Hawaii has adopted a policy regarding the provision of early intervention services. This policy is embodied in Hawaii Act 107-89 which was signed by Governor John Waihee on May 31, 1989. This legislation meets the policy adoption requirements of P.L. 99-457 (now P.L 105-17). It forms HRS paragraphs §321.351 through §321.353. A copy of these HRS paragraphs is included in the Appendix.

## ***PUBLIC PARTICIPATION***

Whenever there is a substantive change proposed to the Part C Early Intervention State Plan, either because of a change in Federal regulations or proposed changes in State policies, arrangements will be made to assure wide public participation in the review and comment on the changes, prior to their adoption or submission to the U.S. Office of Special Education Programs (OSEP).

Reasonable opportunities will be provided for all identified stakeholders, including, but not limited to, the following: parents of infants and toddlers with disabilities (as defined under the state's Part C definition); individuals with disabilities; service providers; community programs serving infants and toddlers in natural environments; pediatricians; institutions of higher education; advocacy agencies; Community Children's Councils; and other agencies and organizations providing services for persons with disabilities and their families.

The process for public comment will include the following:

1. Conduct public hearings in each county of the state;
2. Effectively advertising notice of those public hearings;
3. Publish and make available the policy for not less than 60 days;
4. Provide an opportunity for comment for not less than 30 days; and
5. Review those comments and make modifications, as necessary, prior to finalizing the changes.

In addition to public comment prior to any substantive changes, the HEICC is committed to an enhanced process for public participation in the general evaluation and modification of the early intervention system of services. During FY 1999 an interactive Website is being explored to expand opportunities for public participation through the use of technology.

The HEICC is also committed to beginning a process of chairing a Dialogue Forum on an annual basis in each of the counties of the State. Notification of the planned Dialogue Forum would be provided to all families receiving services in that county, to all providers of services, and to all stakeholders previously identified. The Dialogue Forum will provide an opportunity for the HEICC to maintain a pulse on what is happening in the community, to determine what needs may exist that are not being addressed, to consider what changes may be indicated in service delivery, and to better determine how resources should possibly be reallocated.

## **PART III**

### **REQUIREMENTS RELATED TO COMPONENTS OF A STATEWIDE SYSTEM**

#### **DEFINITIONS**

The State of Hawaii has adopted the definitions in §303.5 - §303.24 of the Part C Federal regulations for use in implementing the State's early intervention program. These definitions are included with this application in the Appendix. Many of these definitions are repeated in Hawaii's state legislation, which is also included in the Appendix.

#### **STATE DEFINITION QF DEVELOPMENTAL DELAY**

For the State of Hawaii the following definitions will be used to determine those who are infants and toddlers with special needs as defined in §303.160. These definitions have been established by State Law and are contained in HRS §321.351

##### ***Developmental Delay***

**Definition.** Developmental delay means a delay in one or more of the following areas of development: cognitive development; physical development (including vision and hearing); communication development; social or emotional development; and adaptive development.

**Eligibility.** Eligibility will be determined by a multidisciplinary team using evaluation instruments standardized on this population, obtaining quantifiable measures, such as percent of delay, standard deviation, and months of delay. Other less quantifiable criteria will also be considered, such as functional status, recent rate of change, prognosis for change in the near future based on anticipated medical/health factors and other factors that may be relevant to the needs of that infant or toddler and the family.

This eligibility is based on the philosophical belief that neither a percentage of delay, nor level of standard deviation should be an absolute or sole requirement to establish eligibility. It is the belief of the Council that a multidisciplinary team can by consensus determine whether any referred infant or toddler has problems of sufficient scope to benefit from early intervention services in the vast majority of cases. There have been no reported problems and no complaints received regarding the implementation of this eligibility criteria during the years of full participation.

A relatively small number of professionals participate in the diagnostic process, helping to assure the comparability of eligibility criteria across the State.

**Multidisciplinary Team.** The composition of the multidisciplinary team will vary, depending on the needs of the infant or toddler. A multidisciplinary team is defined as one consisting of two or more professionals, with the parents/family being considered a professional member of the team.

The team for any child will be determined by the care coordinator in collaboration with

the family and the referring source. It may include a social worker, a special educator or developmental specialist, an occupational therapist, a physical therapist, or speech-language pathologist. It may also include a nurse, a nutritionist, an audiologist, or a psychologist. Each child's pediatrician or primary care provider will be invited to participate. The team will determine the need for additional specialty evaluations. Each member of the team providing an evaluation of the child or family will be responsible for submitting a written report of the evaluation, including any quantifiable results from standardized testing.

***Procedures to Use in Determining Eligibility.*** Both the quantifiable and descriptive information obtained during the multidisciplinary assessment will be used to determine eligibility. If during the IFSP meeting there is not unanimous consensus, majority consensus will prevail. If the parents agree with the majority, there will be no further resolution for the non-consensus. If the parents do not agree with the majority, or if they are evenly divided, the parents may request resolution of the dispute under the Part C regulations included in this application. There has not been a single complaint received from a parent during the previous years of full implementation.

The care coordinator will be responsible for developing and coordinating the report, extrapolating the descriptions of developmental functioning for the IFSP, and for summarizing the results of the evaluations and the recommendations of the professionals.

## ***Biological Risk***

***Definition.*** Biological risk means prenatal, perinatal, neonatal, or early developmental events suggestive of biological insults to the developing central nervous system which increase the probability of delayed development. These are the children under 303.16 (2) who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. It includes, but is not limited to infants and toddlers in the two following categories:

1. Any infant or toddler who has a diagnosed medical (physical or mental) condition with a high probability of resulting in developmental delay: for example, but not limited to, Down Syndrome, Fetal Alcohol Syndrome, AIDS, moderate-severe asphyxia, sensory impairments, SGA, gestational ages under 32 weeks, failure to thrive, hearing loss resulting from chronic otitis media, and infants born to mothers with diabetes, history of substance abuse, or history of mental illness.
2. Very low birth weight infants (1,500 grams or less).

***Eligibility.*** Eligibility within this category will be determined based on a statement/report signed by a physician, indicating the condition which is likely to lead to developmental delay.

## ***Environmental Risk***

***Definition.*** Environmental risk means physical, social, or economic factors which may limit development. Hawaii has elected to include within its eligible population those infants and toddlers who are at risk of having substantial developmental delays if early intervention services are not provided [ §303.16 (b)]. Environmental risk includes, but is not limited to the following conditions:

- a. Birthweight between 1,500 and 2,500 grams, in combination with any other environmental risk factor;
- b. Parental age less than sixteen;
- c. Parental age between sixteen and eighteen and less than a high school education in combination with any other environmental risk factor;
- d. Any existing physical, developmental, emotional, or psychiatric disability in a primary caregiver;
- e. Presence of physical, developmental, emotional, or psychiatric disability in a sibling or any other family member in the home in combination with any other environmental risk factor;
- f. Abuse of any legal or illegal substance by a primary caregiver;
- g. Risk for child abuse and neglect;
- h. Economically disadvantaged family in combination with any other environmental risk factor;
- i. Single parent in combination with any other environmental risk factor; and
- j. Incarceration of a primary caregiver in combination with any other environmental risk factor.

***Eligibility.*** Eligibility as an infant or toddler with special needs because of an environmental risk factor will be established by documentation of the risk factor/factors by the interim care coordinator.

## ***Multiple Categories***

The Council and the Department recognize that at any one time any infant or toddler may be eligible for services based on all three of the preceding definitions. There obviously exists tremendous overlap in the population, so that the same infant who is at environmental risk, may have also been low-birthweight and may be already showing delays. This potential overlap is diagramed on the following page.

The service system will respond to the needs of the individual infant and toddler and their family, irrespective of the category which establishes his/her eligibility for services.

Whenever those needs change, eligibility does not need to be established under a

different eligibility category. The IFSP merely needs to be revised to reflect additional assessment information and what new services are to be provided.

## ***CENTRAL DIRECTORY***

The Hawaii Keiki Information Services System (H-KISS) has been operational since October 1, 1990. On the following page is the public awareness brochure for H-KISS. This is a computerized database, staffed by information specialists (social workers). Included in the database of services and resources are:

1. Public and private early intervention services, resources, and experts available within the State of Hawaii;
2. Research and demonstration projects being conducted in the State;
3. Professional and other groups, nationally and locally, that provide assistance to infants and toddlers with special needs and their families;
4. Perinatal services and resources are also included; and
5. Services for children with special health care needs from birth to age 21, as required under Title V.
6. National and local parent-to-parent organizations.

The Department of Health in the State of Hawaii assures the following in conformance with §303.301 (b), (c), and (d):

1. The central directory is in sufficient detail to:
  - a. Ensure that the general public will be able to determine the nature and scope of the services and assistance available from each of the sources listed in the directory. This will include, but is not limited to, the following information: nature and scope of services, contact person's name, address, telephone number, whether transportation is provided, eligibility for services, and accessibility for persons with disabilities, including the availability of telecommunication facilities for the hearing disabled.
  - b. Enable the parent or other caregiver of an infant or toddler eligible under Part C, as well as service providers and care coordinators, to contact, by telephone or letter, any of the sources listed in the directory.
2. The central directory will have the following characteristics:
  - a. Accessibility to the general public;
  - b. Availability in each geographic region, including rural areas; and
  - c. Accessibility to persons with disabilities.
3. The central directory will be updated at least annually.



To implement the Central Directory, upon the advice and recommendation of the Hawaii Early Intervention Coordinating Council, the Department chose to utilize The Logical Choice (TLC) Information System. This system was developed by the Carolina Research and Development Foundation, a non-profit organization affiliated with the University of South Carolina. The TLC was reviewed and revised following the passage of P.L. 99-457 to focus on the information needs of infants and toddlers with special needs and their families. The database currently contains a total of 1,219 programs under 342 separate agencies.

In addition to operating as the central directory of services, H-KISS is also the central point of contact for early intervention services throughout the state. It is currently also the repository for the early intervention data base and serves as the toll free line for children with special health needs.

All children with special needs and their families who are new to services are linked through the Central Point of Contact to an interim care coordinator to arrange screening and/or evaluation, on-going care coordination, and implementation of services through the IFSP. Refer to the Child Find Section, Central Point of Contact, for a more detailed description of the referral process.

Calls to H-KISS are followed-up on a periodic basis to determine the effectiveness of referrals, document gaps in services, and to provide additional information and assistance in accessing services as needed. In addition, staff participate in the coordination of an information and referral network to facilitate the exchange of information and sharing of resources and training provided by each information and referral service.

Public awareness efforts have included distribution of H-KISS brochures to parents and providers through private and public health and human service agencies statewide, all pediatricians in the state, health fairs, periodic articles in various community publications and newsletters and advertisements in the Health and Sciences Section of the newspaper, and H-KISS presentations to community groups and health and human services professionals.

The diagram on the following page shows the linkage between H-KISS, HEITS, and the Central Point of Contact.

## **COMPREHENSIVE CHILD FIND SYSTEM**

The Department of Health for the State of Hawaii assures that there is comprehensive child find system in place that is consistent with Part B and meets the requirements as outlined in the Part C Regulations to identify, locate, and evaluate all eligible infants and toddlers. The Department is responsible for the implementation of the child find system for infants and toddlers with special needs. The conceptual framework for the flow of services for identification is found on page 25. The Department depends on the advice and recommendations of the Council in child find activities.

**Procedures.** There are three primary means the Department will utilize to assure a comprehensive child find system.

1. **Developmental Screening.** The Department is attempting to assure that each infant and toddler within the State receives regular, periodic developmental screening during the first three years of life. This is to be accomplished by assuring that each young child has a "medical home" and that within that home, developmental screening and appropriate referrals for follow up services are provided. The state has made five specific efforts to encourage this process:
  - a. **Infant-Child Monitoring Questionnaire.** Hawaii has adapted the Oregon version of the ICMQ and is urging its utilization throughout the state as a family-friendly, culturally-sensitive measure to identify infants and toddlers in need of more extensive evaluation. The Zero-to-Three Services Section has provided technical assistance, training, publication of the manual, and distribution of forms to encourage utilization. The ICMQ screening is currently done by the Healthy Start programs, Kamehameha Preschools, Public Health Nurses, and many pediatricians. In addition to the screening itself, activity sheets are distributed to families to assist them in providing activities to stimulate their child's growth.
  - b. **Medical Home Training Program.** For the past twelve years extensive efforts have been provided statewide to educate pediatricians concerning developmental issues in young children. Training has been provided statewide to familiarize pediatricians with developmental screening, to help them understand referral patterns, and to make them aware of community resources to provide early intervention services. Almost all young children in Hawaii have access to health care which should assure they receive routine developmental screening.
  - c. **QUEST Waiver.** An 1115 waiver was approved for Hawaii and became operational on August 1, 1994, to provide a managed care system for virtually all children formerly eligible under Medicaid as well as all families up to 300 of poverty (with a sliding fee premium for those between 133-300 of poverty). This waiver,

along with Hawaii's mandated employer coverage, virtually assures access to health care for all children. All children eligible under the waiver are eligible for full EPSDT benefits. Excluded from the first phase of QUEST are disabled children, those who would qualify under SSI.

- d. **Public Health Nursing Services.** Public health nursing staff provide developmental screening for infants and toddlers without other access to health care. In previous years further training has been provided in developmental screening for nursing staff members. The ICMQ is now the standard for PHN screening.
  - e. **Behavior-Ages and Stages Questionnaire.** Hawaii is involved in field testing the Behavior-Ages and Stages Questionnaire (B-ASQ), a series of seven (7) questionnaires designed by the Early Intervention Program at the University of Oregon to be completed by parents and caregivers about a young child's development in behavioral areas. Each B-ASQ is organized around behavioral domains and the number of items vary according to the age of the child. The B-ASQ is being studied in an effort to find solutions to problems related to prevention, identification and treatment of behavior problems in young children.
2. **Public Awareness.** Public awareness activities will have a primary focus of encouraging the identification of those infants and toddlers in need of services. This will primarily be accomplished through the following activities:
- a. **Central Point of Contact.** H-KISS became the central point of contact for referrals for early intervention services on April 1, 1991. With a single call, a provider can obtain information on services and link a family with an interim care coordinator who will begin the evaluation process.  
  
There is a system in place for assigning an interim care coordinator. This will depend on the source of the referral as well as the information provided. If the information suggests the presence of possible delays or risk factors, the call will be referred and assigned an interim care coordinator who will arrange for a developmental screening. These screenings will be available through a combination of resources which includes physicians, public health nurses, early intervention providers, and care coordinators. If an infant or toddler has already been screened at the time of the initial call, and further assessment is needed, the evaluation is scheduled. The IFSP is developed thereafter. For infants with developmental delays, a referral is made directly to an infant development program for evaluation and development of the IFSP. This system is diagramed on the following page.  
  
The name of the interim care coordinator, and the name of the child and family being referred is documented on the H-KISS Caller

Information Screen and recorded in the Hawaii Early Intervention Tracking System (HEITS). This information is transferred to the H-KISS telephone log and sent to the designated interim care coordinator. A copy of the H-KISS telephone log is included in the Appendix. A parent packet is also sent to the family to let them know which program will be contacting them to arrange services and to provide them with additional information on early intervention services.

- b. ***Other Media Events.*** As described in the component on "Public Awareness", there will be a variety of media and publicity activities which will focus specifically on identification of developmental delays and child find activities. Specifically it is planned that developmental screening will be made a specific part of community health fairs and be made available periodically in shopping malls in an effort to make developmental screening as community-based and accessible to difficult-to-reach families as possible.
- c. ***Pediatric Outreach.*** In an effort to assure the greatest possible collaboration with pediatricians, copies of the annual report on early intervention services are distributed to all pediatricians. Informational-type forums which provide pediatricians with up-to-date information on early intervention services under Part C are held periodically. Part of this strategy includes having a pediatrician as a member of the HEICC Council and its Executive Committee.

- d. **Specific Brochures.** A Developmental Checklist for Young Children have been developed and are included in the Appendix. This is made available to families during in a variety of ways. A Keiki (Hawaiian for "child") Find brochure has been developed appears on the following page. This is distributed widely to pediatricians and agencies.
3. **Coordination.** The Department assures that the child find system is coordinated with all other major efforts to locate and identify children which are conducted by other State agencies responsible for administering various education, health, and social service programs relevant to infants and toddlers and their families. This includes Part B activities, Title V Maternal and Child Health Activities, Medicaid's EPSDT, Developmental Disabilities, and Head Start. Specifically for Hawaii, the following will be primary resources for coordination of Child Find activities:
- a. **Medical Home Project.** The Department works very closely with this effort as it seeks to provide training for all physicians in the State in the identification of the psycho-social problems that constitute the "new morbidity" in children. Information concerning resources for infants and toddlers with special needs has been a major focus of the project's activities. In the Appendix is a publication entitled, "Framing the Future" that vividly describes the role of the Medical Home in early intervention, defining the close relationship in Hawaii between the Part C system and pediatricians.
  - b. **Part B Child Find.** The activities will be coordinated annually with the Part B "Operation Search". A copy of the most recent Part B brochure is included in the Appendix. It lists the H-KISS Central Point of Contact number for children from birth to three.
  - c. **DHS Notification Regarding EPSDT.** Information brochures on the central directory are available for distribution at intake to families receiving public assistance from the Department of Human Services. This brochure is also available to families applying for QUEST.
  - d. **Community Programs Serving Environmentally-At Risk Infants and Toddlers.** An important portion of the Hawaii system is the "reverse referral pattern". There are a number of agencies in the state serving environmentally at-risk infants and

toddlers. Their data systems are linked with the statewide tracking system to ensure information on all eligible children is centrally located. These newborns are eligible under the umbrella of Part C services. However they will be identified under existing agencies, under contract with the Hawaii's Maternal & Child Health Branch. Collaboration will be in place to assure that there is care coordination and an IFSP for each of these families that meets the requirements of Part C regulations.

The Department assures that there not be unnecessary duplication of effort by the various agencies involved in the Part C child find system. The Department will make use of the resources available through each public agency in the State to implement the child find system in an effective manner.

4. ***Referral Procedures.*** The child find system will be linked to the central directory to provide for immediate access to the care coordination and tracking system. Referrals may be received from any source, including hospitals, physicians, parents, day care programs, local education agencies, public health facilities, other social services agencies, or other health care providers. Upon referral of a child who either has a delay as identified by a developmental screening, or a biological or environmentally eligible risk factor, an interim care coordinator will be assigned.
5. ***Dissemination of Information.*** The Department notifies primary referral agencies of the requirement for timely referral of eligible infants and toddlers through the regular mailing of brochures, personal contacts and presentations before all primary referral sources. The Department has established methods to determine the extent to which primary referral sources disseminate information on the availability of early intervention services to parents by providing all primary referral sources with a supply of materials on early intervention services in the state and by keeping a record at the single point of contact of how the family was informed of services. This information will be reviewed annually.
6. ***Primary Referral Sources.*** Within the State of Hawaii these sources are understood to be primarily the medical home of the child, hospitals, day care programs, local educational agencies, public health facilities, other social service agencies, and other health care providers. Parents and other family members or friends are also considered primary referral sources.

The Department and Council, through interagency collaboration and community public awareness efforts, will make all primary referral sources aware of the mandate to refer young infants and toddlers within two days of having suspected or identified a delay, or eligible condition or risk factor. This will be accomplished through a variety of public awareness efforts.

7. ***Timelines.*** Upon assignment of the interim care coordinator, information will be entered in the tracking system to assure that the evaluation and assessment and the IFSP are completed within 45 days of referral. There is a policy for presumptive eligibility. Based on initial information, an interim support plan may be implemented.

## ***EVALUATION AND ASSESSMENT***

The Department of Health for the State of Hawaii has made evaluations and assessments available for each eligible infant and toddler in accordance with §303.322 since October 1, 1990. The Department is responsible for ensuring that these requirements are implemented by all affected public agencies and service providers in the State.

***Definitions.*** The following are the applicable definitions which will be used relative to this component:

1. ***Evaluation*** means the procedures used by appropriate qualified personnel to determine an infant or toddler's initial and continuing eligibility as defined in HRS §321-351, including determining the developmental status of the infant or toddler in the areas of cognitive development, physical development (including hearing and vision), communication development, social or emotional development, and adaptive development.
2. ***Assessment*** means the ongoing procedures used by appropriate, qualified personnel throughout the period of the infant or toddler's eligibility to identify:
  - a. The infant or toddler's unique strengths and needs in collaboration with parents;
  - b. The family's resources, priorities, and concerns related to the development of the infant or toddler;
  - c. The nature and extent of early intervention services that are needed by the infant or toddler and their family to meet these unique strengths and needs; and
  - d. This assessment process will include whatever reassessments are needed prior to the annual, or earlier, review of the IFSP.

***Policies for Child and Family Assessment.*** The following general policies have been adopted by the Council to facilitate a family-centered assessment process:

- \* Families will be given repeated opportunities over time to identify their resources, priorities, and concerns.



- \* A "For Family" checklist will be provided to the family prior to the IFSP interview which will enable them to be prepared to identify areas of information, needed services and supports.
- \* The conducting of the assessment in their home will be offered as an alternative to the family.
- \* Every effort will be made to establish a partnership with the family to maximize parent participation in the assessment process.
- \* The family assessment will focus only on assessing family strengths as they relate to family identified needs.
- \* Assessments will be conducted in more than one setting and over time.
- \* Professionals will share all results with the family, both orally and in writing, using language free of jargon.
- \* The process will allow for an interim IFSP in situations where the infant or toddler is clearly in need of services, but the assessment has not been completed.
- \* Assessments will be conducted with a respect for the family's privacy, integrity, and ability to make decisions for themselves.
- \* In establishing child and family outcomes, the family will be provided the opportunity to speak first, with the outcomes generated by the family.
- \* The outcomes will be written in the language of the family.
- \* The family will be able to prioritize their child and family outcomes.

***Evaluation and Assessment of the Child.*** The evaluation and assessment of each infant and toddler will be conducted by a multi disciplinary team, determined by the unique strengths and needs of the individual infant or toddler. Each team member will meet the standards as established by the Personnel Standards Component. The Department assures that these personnel will have been trained to use appropriate methods and procedures. The Department further assures that the evaluation and assessment will be based on informed clinical opinion.

Each evaluation and assessment will include the following components:

1. A review of the infant or toddler's current health records and medical history;

2. An evaluation of the infant or toddler's level of functioning in each of the following developmental areas:
  - a. Cognitive development,
  - b. Physical development, including vision and hearing,
  - c. Communication development,
  - d. Social or emotional development,
  - e. Adaptive development; and
3. An assessment of the infant or toddler's unique strengths and needs and identification of appropriate early intervention services in each of the foregoing areas.

**Family Assessment.** The family assessment has been designed to determine the resources, priorities, and concerns of the family related to enhancing the development of the child. Policies have been approved by the Council which would assure that the parents understand that this assessment is voluntary, and will in no way jeopardize the provision of needed services by the infant or toddler.

Any assessment conducted will be conducted by personnel trained to utilize appropriate methods and procedures. The assessment will be based on information provided by the family through a personal "talk-story" interview. The assessment will incorporate the family's description of its strengths and needs related to enhancing their infant or toddler's development.

The family assessments will be family-directed and designed to determine the resources, priorities and concerns of the family to enhance the development of their child.

**Timelines.** The evaluation and initial assessment of each child and family will be completed within 45 days of referral. In the event of exceptional circumstances that make it impossible to complete the evaluation and assessment within 45 days of referral, for example if the infant or toddler is ill, these exceptional circumstances will be documented. If appropriate, an interim IFSP, under presumptive eligibility, will be implemented.

***Nondiscriminatory Procedures.*** The Department assures that nondiscriminatory procedures will be utilized in all evaluation and assessment activities. These procedures include the following requirements:

1. Tests and other evaluation materials and procedures are administered in the native language of the parents or other mode of communication, unless it is clearly not feasible to do so;
2. All assessment and evaluation procedures and materials that are used are selected and administered so as not to be racially or culturally discriminatory;
3. No single procedure is used as the sole criterion for determining a child's eligibility for early intervention services; and
4. Evaluations and assessments are conducted by qualified personnel.

## ***INDIVIDUALIZED FAMILY SUPPORT PLANS (IFSP)***

**Introduction.** The Department of Health for the State of Hawaii has developed plans and procedures for the development of the IFSP through the Hawaii Early Intervention Coordinating Council's Partnership Committee. Those plans and procedures were subsequently submitted to the Executive Committee and the full Council for their approval. A policy decision was made to substitute the word "support" for the word "service" as appears in P.L. 105-17 and its regulations.

The ***Individualized Family Support Plan*** has been defined as a dynamic, voluntary plan of action and support developed by families and professionals that emanates from the families' expressions of needs and goals. The IFSP is based on the following assumptions:

- \* The most important thing that happens when a child is born with special needs is that a child is born. The most important thing that happens when a couple become parents of a child with special needs is that a couple becomes parents.
- \* Families are competent caregivers.
- \* Families have a right to complete and unbiased information regarding their child with special needs.
- \* Families have a right to choice and with choice comes responsibility and accountability.
- \* Families should determine their level of participation in the IFSP process.
- \* Families are the primary decision makers about service needs and child and family priorities.
- \* Families are self-defined.
- \* Families are entitled to privacy.
- \* Family-professional partnerships based on mutual respect, trust and commitment are essential to a successful IFSP process.

The following are the desired outcomes of the IFSP process:

- \* The family's care giving, decision-making, advocacy and teaching roles will be enhanced.
- \* The family will maximize their control over the services and supports they receive.
- \* The IFSP process will support the whole family.
- \* The intervention services will encourage the integration of the child and family into natural settings within their community.
- \* Individual family cultural values, customs and beliefs will be recognized

and affirmed as valid and important.

- \* The IFSP process will not be intrusive nor place unreasonable burdens on the family.
- \* The IFSP process will be both dynamic and flexible and be responsive to the changing needs of the child and family.
- \* Family-professional partnerships will be promoted, nurtured, and strengthened.
- \* Families will make optimal use of informal and formal community resources.

In using the term "voluntary" the Council recognizes that any family may elect not to participate in the assessment of family resources and needs portion of the IFSP. In that event, family goals and objectives in the IFSP would relate only to the assessment and services needed by the infant or toddler.

**Care Coordination.** To assure the successful implementation of the IFSP, the Hawaii Early Intervention Coordinating Council has elected to use the term "care coordination" in lieu of "service coordination". Care Coordination is defined as an ongoing service, system and process of shared responsibility between families and professionals that identifies strengths and needs and assists in obtaining coordinated, appropriate services and resources.

The family should be the final decision maker on the IFSP team. Therefore, parents will be named as co-care coordinators, unless they decline to be so named. Parents are to be given complete and unbiased information, support and training to develop and enhance their resources, skills, and confidence. The naming of parents as co-care coordinators will not diminish the responsibility and accountability of the agency or program to provide care coordination services.

The family should have the right to choose the care coordination option that best meets their needs. Care coordinators will come from a variety of disciplines, including health, education, social work, nursing, mental health, and other related fields, and include both professionals and paraprofessionals. This means that early intervention personnel will take on expanded roles in their work with infants and toddlers with special needs and their families.

A formative evaluation of Hawaii's care coordination system was conducted in 1990 with favorable results to continue its services. Changes were made to enhance the system as a result of the 1990 evaluation study. The Zero-to-Three Hawaii Project continues to obtain informal feedback from care coordinators, family members, and other early intervention service providers to enhance care coordination services to meet the diverse needs of families within their communities.

A second formative evaluation study is planned to address three concerns. First, to determine if service providers within Hawaii's early intervention system are responsive to the changing needs, concerns, and priorities of families who care for infants and toddlers with special needs in a family-centered and culturally competent manner. Second, to determine if the administrators of the Department of Health are responsive to training and support needs of service providers to be able to fulfill their care coordination functions. Finally, to determine if the Department of Health's policies and procedures for providing care coordination is in continuing compliance with the federal legislation.

Listed below are the evaluation questions to be asked in the planned study:

1. To what extent are the principles of family-centered care and cultural competency practices apparent in the provision of care coordination services?
2. To what extent is the Department of Health able to recruit and maintain qualified care coordinators to fulfill all functions of care coordination under P.L. 105-17?
3. To what extent are administrators of the care coordination system responsive to the training needs to prepare care coordinators and family members to work together to fulfill all functions of care coordination?
4. To what extent are families and care coordinators able to work together to fulfill all functions of care coordination?
5. To what extent does care coordination service provide continuity of early intervention services?
6. To what extent does care coordination reduce duplication of services?
7. To what extent do care coordination services maintain the integrity of families?

**General.** The Department of Health for the State of Hawaii has previously assured that after October 1, 1990, a written IFSP was in place for every eligible infant and toddler. (See the preceding section for a description of the evaluation and assessment procedures.)

Each IFSP will identify the care coordinator who is responsible for providing care coordination services for that family. Since October 1, 1990, all mandated services specified within the IFSP have been made available to eligible infants and toddlers and their families. The Department of Health, as the lead agency, assumes the responsibility for resolving any dispute between agencies as to who has responsibility for developing or implementing an IFSP and will, when necessary, assign responsibility for development and implementation of the IFSP.

The plan will be developed jointly by the family and appropriate qualified personnel involved in the provision of early intervention services. It will be based on a multidisciplinary (consisting of two or more professionals, including the family) evaluation and assessment of the child, and the child's family. The IFSP will include the services necessary to enhance the development of the child and the capacity of the family to meet the special needs of the child.

**Development, Review, and Evaluation.** Every infant and toddler referred through the central point of contact for entry into the system and determined to be eligible will have an initial IFSP meeting conducted within 45 calendar days of the day of referral. The care coordinator will be responsible for conducting a review of the IFSP every six months, or earlier, if requested by any member of the multidisciplinary team (including the family). This review may be by a meeting or another means that is acceptable to the parents and other members of the multidisciplinary team. The periodic review will determine and document the following:

1. The degree to which progress toward achieving the outcomes is being made; and
2. Whether modification or revision of the outcomes or services is necessary.

In addition to the required semi-annual review that may or may not include a meeting, a meeting will be conducted at least annually to evaluate the IFSP for the infant or toddler and family to revise its provisions. The results of any current evaluations and other information available from the ongoing assessment of the infant or toddler and family must be used in determining what services are needed and will be provided.

Arrangements for the IFSP meeting must be made with, and written notice provided to, the family and other participants early enough before the meeting date to ensure that they will be able to attend. The IFSP meetings will be scheduled and conducted in settings and at times that are convenient to families. The meetings will be conducted in the native language of the family or other mode of communication used by the family, unless it is clearly not feasible to do so.

***Participants in the IFSP Meetings and Periodic Reviews.*** The following persons will participate in the IFSP process:

1. The parent(s) and/or legal guardians of the infant or toddler;
2. Other family members, as requested by the parent, if feasible to do so;
3. An advocate or person outside of the family, if the parent requests that the person participate;
4. The interim care coordinator who has been working with the family since the initial referral of the child for evaluation, or who has been designated by the public agency to be responsible for the implementation of the IFSP;
5. The persons directly involved in conducting the evaluations and assessments (including the child's medical home); and
6. As appropriate, persons who will be providing services to the infant or toddler and family.

If one of the persons listed above is unable to attend the IFSP meeting, arrangements will be made for the person's involvement through other means, including participating in a telephone conference call, having a knowledgeable authorized representative attend the meeting, or making pertinent records available at the meeting. Each periodic review of the IFSP must provide for the participation of these same persons.

***Content of the IFSP.*** Copies of the IFSP forms and the "For Families" checklist currently being used for each target population in the State of Hawaii are included in the Appendix. Each IFSP will contain the following information:



1. **Information About the Infant or Toddler's Status.** The IFSP will include a statement of the infant or toddler's present levels of physical development, including vision, hearing, and health status, cognitive development, communication development, social or emotional development, and adaptive development. This information will be based on professionally acceptable objective criteria.
2. **Family Information.** With the concurrence of the family, the IFSP will include a statement of the family's resources, needs, concerns and priorities related to enhancing the development of the infant or toddler.
3. **Outcomes.** The IFSP will include a statement of the major outcomes expected to be achieved for the child and family, and the criteria, procedures, and timelines used to determine:
  - a. The degree to which progress toward achieving the outcomes is being made; and
  - b. Whether modifications or revisions of the outcomes or services are necessary.
4. **Early Intervention Services.** The IFSP will include a statement of the specific early intervention services necessary to meet the unique needs of the infant or toddler and the family to achieve the outcomes identified in (3) above. This statement will include:
  - a. **Frequency and Intensify.** The number of days or sessions that a service will be provided, the length of time the service is provided during each session, and whether the service is provided on an individual or group basis will be specified.
  - b. **Location.** It will be specified as to where the service will be provided (e.g., in the infant or toddler's home, early intervention center, hospital, clinic or other setting) as appropriate to the age and needs of the infant or toddler and family.
  - c. **Method.** How a service is provided will be specified.
  - d. **Payment.** If payment arrangements are necessary, the sources of payment for the service will be specified.
  - e. **Natural Environments.** Each IFSP will contain a statement of the natural environment in which early intervention services shall appropriately be provided, including a justification of the extent, if any, to which the services will not be provided in a natural environment.

5. **Other Services.** To the greatest extent possible, the IFSP will include what medical and other services the infant or toddler and/or their family needs but are not services mandated under Part C. The IFSP will also specify the steps that the care coordinator will take to assist the family in accessing these services through the use of public and private resources. This includes routine medical services, such as immunizations and well-child care, with special emphasis on assuring that all children in the Part C system are up-to-date on immunizations.
6. **Dates and Duration of Services.** The IFSP will include the projected dates for initiation of the services under the preceding item 4 and the anticipated duration of these services.
7. **Care Coordinator.** The IFSP will include the name of the care coordinator from the profession most immediately relevant to the child's and family's needs, and who will be responsible for the implementation of the IFSP and coordination with other agencies and persons. As previously discussed under "Comprehensive Child Find System" and interim-care coordinator will be assigned at the time of the referral. During the IFSP meeting, this person may remain as the care coordinator, or the family may select a new care coordinator from the professional most immediately relevant to the infant, toddler, or family's needs.
8. **Transition to Preschool/Community Services.** Each IFSP will include the steps to be taken upon the initiation of early intervention services to support the transition of the toddler, upon reaching the age of three, to the preschool services under Part B of IDEA or to other community services, as may be appropriate and based on family preferences. Each IFSP, including the initial IFSP, will contain a transition plan. Transition services will include the following components:
  - a. Discussion and training for parents, encouraging them to voice their dreams and expectations for their child, regarding potential future services, placements, and other matters related to their child/family's transition;

- b. Procedures to prepare the toddler for changes in service delivery, including steps to help the toddler/family adjust to, and function successfully in a new setting;
- c. With written parental consent, the transmission of information about the child to the local educational agency, or other community service provider, to ensure continuity of services, including provision of evaluation and assessment information and copies of IFSPs that have been developed and implemented;
- d. For children possibly eligible under Part B, by the time the toddler is two and one-half years of age, the child's home school will be notified. At least 90 days prior to, (and at the discretion of the all parties, up to six months before), the child's date of eligibility under Part B, a meeting will be convened to discuss service options. That meeting will include at least the family, the care coordinator, and a representative from the school district for Part B;
- e. For children possibly eligible under Part B, the Part C care coordinator will continue to provide care coordination services for the family until a new care coordinator is named at the conclusion of the IEP meeting; and
- f. For children probably not eligible under Part B, at least 90 days prior to the child's third birthday (and at the discretion of the family), a meeting will be convened of the family, the care coordinator, and any agency representatives who may likely serve the child following the third birthday.

9. **Parent Signature.** The IFSP will include parent signature(s) to acknowledge parents as the primary decision makers on the IFSP team. Parent signatures provide consent for the provision of early intervention services.
- The contents of the IFSP will be fully reviewed with the parents and informed written consent obtained from the parents prior to the provision of early intervention services outlined in the IFSP. If the parents do not provide consent with respect to a particular early intervention service, that service will not be provided. This lack of consent by the parent will be noted on the IFSP by that recommended service. The early intervention services to which parental consent is obtained will be provided.

10. **Identified Services and Support Needs.** The Hawaii Early Intervention Coordinating Council has established as policy that the IFSP should reflect services and support needs identified by families and professionals together -- regardless of the availability of the services, or whether they are mandated services.

**Provision of Interim Services.** Early intervention services for an eligible infant or toddler and family may commence before the completion of the evaluation and assessment if the following conditions are met:

1. Parental consent is obtained.
2. An interim IFSP is developed that includes:
  - a. The name of the care coordinator who will be responsible for the implementation of the interim IFSP and the coordination with other agencies and persons; and
  - b. The early intervention services that have been determined to be needed immediately by the infant or toddler and the family; and
3. The evaluation and assessment are completed within 45 days of initial referral.

**Parental Consent.** The contents of the IFSP will be fully reviewed and explained to the parents and informed, written consent from the parents, obtained prior to the provision of early intervention services. (See Parent Signature on page 41.)

**Good Faith Effort.** Each agency or person who has a direct role in the provision of early intervention services is responsible for making a good faith effort to assist each eligible infant or toddler and family in achieving the outcomes in the infant or toddler's IFSP.

## **STATEWIDE SYSTEM OF EARLY INTERVENTION SERVICES**

The Council assigned to its Community Services Committee responsibility for designing the overall early intervention service delivery system for infants and toddlers with special needs and their families. The following philosophic statement was developed to guide the development, implementation, and expansion of the system:

- \* Families are competent.
- \* Families are an important social structure that we want to preserve.
- \* Families should and can make decisions about their interactions with agencies and service providers; they should be supported to be coordinators and decision-makers for their children.
- \* Care coordination should begin as soon as a child is identified as at risk.
- \* There is an overlap between eligibility categories. Children may move between, or be in more than one category simultaneously.
- \* Services are driven by child and family needs. The family may have needs independent of the child's needs.
- \* Transition planning should be a part of every family plan from the initiation of early intervention services.

### ***System of Services***

The system of services, as outlined on the following pages, was recommended by the Community Services Committee to the HEICC. It received their unanimous approval on April 24, 1991. It was also noted that any system is not static, and therefore will be revised as needs change.

### ***Flow of Services***

The chart on the following page depicts the entire cohort of children between birth and age three, including both those identified as "at risk" as well as those who have been screened and determined to be "not at risk". The flow chart supports the belief that children may move from one eligibility category to another, or may simultaneously be eligible in more than one category by utilizing overlapping circles to show the relationship among the definitions.

## ***Description of Services***

The following is a list of the services that have been identified as being needed by eligible families. The list is divided into specific services within service categories and expands the early intervention services found in Section 672 (Definitions) of P.L. 105-17. This list of services includes services mandated by P.L. 105-17 as well as services, while not mandated, are often needed by families. The Department of Health, as lead agency, is responsible for providing only the mandated services. However, to the extent possible, links will be made with other agencies in the community to provide child care, subsistence assistance, and adaptive equipment.

### ***Early Intervention Services***

1. ***Screening/Assessment:*** The process of identifying and evaluating children who have special needs or are at-risk of developmental delays through the collaboration of families and professionals so that recommendations can be made for appropriate, acceptable intervention plans to meet the identified needs of the child and family.
2. ***Special Instruction/Developmental Intervention:*** These are structured interventions in home and/or facility, designed to provide educational, developmental, and therapeutic treatment activities that will help the infants/toddlers with special needs attain their maximum potential.
3. ***Occupational Therapy:*** Therapy or remedial treatment that focuses on fine motor dexterity and daily living skills.
4. ***Physical Therapy:*** Therapy or remedial treatment that focuses on gross motor skills and muscle coordination.
5. ***Speech/Language Therapy:*** Therapy designed to develop communication skills.
6. ***Audiology:*** The treatment of hearing impairments.
7. ***Recreational Therapy:*** Recreational services provided through specialized programs at parks or other recreational areas for the treatment of the child through leisure activities.
8. ***Assistive Technology:*** Modification of equipment specifically for use by individuals with disabilities, such as mobility aids (e.g., wheelchairs, crutches), sensory aids (e.g., talking books, glasses, hearing aids), standing boards, etc.

### ***Medical/Health Care***

1. ***Developmental Monitoring.*** Regular, periodic follow-up of child's development, using developmental screens and well-child checkups.

2. **Nutritional Support.** Information provided to families/caregivers about how they can meet the nutritional needs of their children. May include a dietary analysis and recommendations.
3. **Medical Monitoring.** Regular, periodic follow-up of a child's medical problems.
4. **In-Home Medical Support.** Medical care provided to the child in his/her home.
5. **Medical Equipment.** Equipment necessary to maintain treatment and/or health, including disposable supplies (e.g., syringes, pads) and durable items.

### **Family Services**

1. **Psychological Services.** Planning and managing a program of psychological services, including psychological counseling for children and parents, family counseling, consultation on child development, parent training, and education programs.
5. **Care Coordination Services.** Working with families and service providers to ensure that services identified within the IFSP are provided.
6. **Child Care.** Care for child on a regular basis (full or part-time), in either a group facility or at an individual's home, so parent/caregiver can go to work, school, or have free time on a regular basis.
7. **Respite.** Care for child on a temporary basis so parent/caregiver can have free time for personal errands, entertainment, etc. May occur daytime or evenings, at home of the child or care giver.
8. **Transportation.** Transportation provided to the child and/or parent/caregiver to provide the means for them to get to and from their appointments, programs, and leisure activities.

## ***Family Education***

1. ***Information Regarding Diagnosis and Prognosis.*** Providing information to parent/caregiver, family member, or service provider (with permission) about a child's specific diagnosis and prognosis.
2. ***Information Regarding Community Services.*** Providing a caller with up-to-date, complete information on all appropriate resources available, including how a needed service may be accessed.
3. ***Caregiver Education and Training.*** Information provided to parents/caregivers, in either a structured program or one-to-one, to assist them in caring for their child, such as child care, feeding techniques, therapeutic techniques, household management, etc.

## ***Family Support***

1. ***Support Groups.*** Formal sessions for parents or caregivers, siblings, or other family members of a child with special needs to provide emotional support and information sharing. These are usually run by a professional.
2. ***Parent-to-Parent Groups.*** Formal sessions for parents to provide emotional support and information sharing with other parents; sessions are organized and run by other parents of children with special needs.
3. ***Social Work/Counseling Services.*** Formal sessions (individual or group) for parents or other family members to assist them in coping with their situation. The sessions are run by professionals and may include issues about family, marital, and parent-child relations.
4. ***Regular Home-Visiting.*** Regular visits to the home (usually once/week) by a professional or paraprofessional to: assist parent/care giver in caring for the infant/toddler; provide informal support; model appropriate parent-child interaction; provide information on child development, etc.
5. ***Periodic Home-Visiting.*** Occasional visits to the home (once/quarter), generally by a professional (PHN) to review the progress of the child/family and make recommendations as needed.
6. ***Recreational/Leisure Activities.*** Recreational activities for infants and toddlers with special needs and their families, that are primarily of a social nature and intended to enhance the quality of life; provided in an integrated community setting as much as possible.



7. Subsistence Assistance. Cash, subsidies, or vouchers given either directly to a family or to a creditor for a specific purpose (e.g., housing, food, job training).

### ***Natural Environments***

To the maximum extent appropriate to the needs of the child and family, early intervention services will be provided in natural environments, including the home and community settings in which children without disabilities participate. Natural environments mean settings that are natural or normal for the child's age peers who have no disability.

To assist families in accessing natural environments, if the parent's choice is not the home, staff resources will be provided to assist the family in accessing financial assistance for preschool or child care services. Training and support is also available for child care providers and preschools to enable them to meet the needs of infants and toddlers with disabilities.

### ***Timetables for Serving All Eligible Infants and Toddlers***

The Department of Health for the State of Hawaii assures that appropriate early intervention services are available for all eligible infants and toddlers. Part C does not apply to any child with disabilities receiving a free, appropriate (FAPE) education under Section 619 of Part B of IDEA.

The Authorization for Services Form, shown on the following page, was developed to provide a mechanism to pay for eligible early intervention services identified as needed on the IFSP, but not available as part of a program.

## ***PUBLIC AWARENESS PROGRAM***

The Department of Health for the State of Hawaii assures that it has developed a public awareness program that will provide the following information to the public:

1. Information on early intervention programs and services throughout the State.
2. Information on the child find system which includes information on the purpose and scope of efforts to identify infants and toddlers with special needs, how to make referrals for services, and how families may gain access to a comprehensive, multi disciplinary evaluation and other early intervention services.
3. Information on how to access the central directory of services.

The expected outcomes of the public awareness effort are as follows:

1. Generate public awareness, acceptance and support for early identification and early intervention services for infants and toddlers with special needs and their families.
2. Prompt earlier identification of infants and toddlers with special needs and their families.
3. Foster public access to the central directory of services.
4. Foster public support and acceptance for future funding of early intervention services.

The following strategies have been approved by the Hawaii Early Intervention Coordinating Council to implement the public awareness program.

### **1. *Brochures***

- a. Develop a variety of media for various target groups (e.g., parents, providers of services, legislators) about the central directory of services; to provide information on developmental guidelines and milestones, as well as on handicapping conditions; values and benefits and the availability of early intervention services and family support services, and where/how to make timely referrals; and to provide information on prevention of handicapping conditions.
- b. Develop brochures and related informational materials at an appropriate reading level (approximately 4th grade) and in various languages (e.g., Samoan, Ilocano, Tagalog).
- c. Brochures will be distributed to all pediatricians, health clinics, family physicians, Healthy Start programs, day care and nurseries, hospitals, dental offices, social services offices, churches, state offices, WIC clinics, and birthing and parenting classes. (This list is not exclusive.)

## 2. ***Advertising Specialty Items***

- a. Have the central directory telephone number printed on peel-off stickers that can be placed on a telephone, in a telephone book, or elsewhere for easy reference.
- b. Have the central directory telephone number with a brief description of the purpose of the H-KISS directory printed on index cards that can be placed in people's telephone directory.
- c. Distribute the stickers, index cards, and pencils at health and children's fairs, conferences (Early Intervention, SPIN, DAP), public forums, etc.

## 3. ***Posters and Flyers***

- a. Develop a poster featuring the central directory telephone number.
- b. Develop other posters featuring developmental guidelines and milestones of infants and toddlers, prevention and child find.
- c. Post posters and flyers in public areas (e.g., physician's offices, health clinics, schools, libraries, hospitals, dental offices, social services offices, churches, buses, etc.).

## 4. ***Newsletter and Filler Advertisements***

- a. Produce a newsletter for statewide distribution on early intervention. Articles will address what is happening in the state and present current issues, legislation, opinions from families and professionals, and techniques for working with infants and toddlers.

The newsletter will become a forum of ideas shared by professionals and families. Issues are published quarterly. A sample issue is included in the Appendix.

- b. Take advantage of all existing organizational newsletters (e.g., SPIN, Commission on Persons with Disabilities, Healthy Mothers/Healthy Babies; PATCHWORKS, FOCUS on Children, Youth and Families, etc.) by submitting articles, announcements, advertisements, etc. on an on-going basis.
- c. Develop public service and paid filler advertisements with the telephone number of the central directory of services in various size matching the column width of various newspapers to be printed in newspapers periodically.

## 5. ***Newspaper Articles***

- a. Prepare articles to cover a broad range of news/stories about new programs, continuing programs, vital services, answers to frequent questions, the impact of services on infants and toddlers with special needs and their families, etc.

- b. Prepare press releases for media.
- c. Solicit letters to the editor.
- d. Solicit articles from HEICC members, from the different units within Family Health Services Division and other early intervention programs for release for the news media.

6. ***Radio and Television***

- a. Develop on-going Public Service Announcements (PSAs) regarding prevention, early intervention, developmental guidelines and milestones, child find, and the central directory of services.
- b. Develop public service and paid advertisements featuring the central directory of services.

7. ***Conference and Exhibit Displays***

Participate in conference and exhibit displays by distributing the brochures, telephone stickers, conducting developmental screening and other health screening (e.g., support free dental check-ups).

8. ***Networking***

Coordinate with the State Planning Council on Development Disabilities to sponsor monthly brown bag lunch network meetings to discuss current issues relating to individuals with special needs and their families.

Develop cooperative advertising with private businesses to promote early intervention and H-KISS services. Public service announcements will be delivered via milk cartons, bread bags, etc.

Develop contact with various community leaders to initiate a grass roots campaign for early intervention services in each community.

9. ***Speakers Bureau***

- a. Coordinate with SPIN to expand their speakers bureau for public presentations.
- b. Coordinate with SPIN to provide training for speakers.

10. ***Annual Conference***

- a. Collaborate in a statewide annual conference on early intervention and early childhood issues and other special events. Co-sponsorship of the conference will be encouraged by other relevant organizations and programs.
- b. Use the conference as a focal point for educating legislators and other policymakers regarding early intervention and family issues.

- c. Provide recognition during the conference for those in the community who have rendered outstanding service in the area of early intervention.

11. ***Annual Report***

Use the annual report, required by the Hawaii Early Intervention Coordinating Council under P.L. 105-17, to increase awareness of early intervention both locally and nationally through distribution of the report. A copy of an annual report is included in the appendix.

12. ***Photography and Videotaping***

Capture on 35 mm film, slides or videotape, professionals, families, and infants and toddlers who have special needs. To create visual images to heighten awareness of the services provided, to generate support for programs, and to celebrate the lives of the families and children receiving early intervention services.

13. ***Training and Presentation Materials***

Collaborate with staff members to develop local and national training and presentation materials. Script development as well as the design and production of materials to enhance the understanding of concepts used in early intervention.

14. ***Child Advocacy***

Commitment to address the needs and issues impacting all children. To promote a quality of life that is safe and secure, and provides equal access to health and education.

15. ***Public Awareness Brochures***

Included in the Appendix are copies of the brochures that are not included elsewhere in this document.

## ***PERSONNEL STANDARDS***

The Department of Health for the State of Hawaii has established policies and procedures relative to the establishment and maintenance of standards to ensure that personnel necessary to provide early intervention services to eligible infants and toddlers are appropriately and adequately prepared and trained.

### ***General Definitions Relative to Personnel Standards***

For personnel standards, "appropriate professional requirements in the State" means entry level requirements that:

1. Are based on the highest requirements in the State applicable to the profession or discipline in which a person is providing early intervention services; and
2. Establish suitable qualifications for personnel providing early intervention services under this part to eligible infants and toddlers and their families, who are served by State, local, and private agencies.

The "highest requirements in the State applicable to a specific profession or discipline" means the highest entry-level academic degree needed for any State approved or recognized certification, licensing, registration, or other comparable requirements that apply to that profession or discipline.

"Profession or discipline" means a specific occupational category that:

1. Provides early intervention services to infants and toddlers eligible under this part and their families;
2. Has been established or designated by the State; and
3. Has a required scope of responsibility and degree of supervision.

"State approved or recognized certification, licensing, registration, or other comparable requirements" means the requirements that the Legislature of the State of Hawaii has enacted or has authorized a State agency to promulgate through rules to establish the entry-level standards for employment in a specific profession or discipline in Hawaii. It is recommended, but not required, that personnel receive certification in an infancy focused specialization such as the Infant Interdisciplinary Specialization (IIS) certification.

## ***Highest Professional Standards by Discipline for Hawaii***

The standards that will be required for early intervention staff are listed below by discipline:

<u>Discipline</u>	<u>Highest Professional Standard</u>
Audiology	State license; requires Master's degree from accredited program, passing national exam and completing internship.
Nursing	State license as Registered Nurse; requires graduation from accredited nursing program and passing national exam.
Nutrition	Requires either M.P.H. in Nutrition or M.S. in Human Nutrition from accredited program and being a Registered Dietician (RD) with the American Dietetic Association; no state license
Occupational Therapy	Must be a Registered OT (OTR) by the American OT Association; requires a Bachelor's degree in Occupational Therapy from an accredited program and passing national exam; no state license
Physical Therapy	State license; requires Bachelor's degree in Physical Therapy from an accredited program, passing national exam and certification by the American PT Association.
Pediatrics	State license as a Physician and Surgeon; Board-Eligible Pediatrician by the American Academy of Pediatrics which requires completion of 3 year Pediatric internship.
Psychology	State license as Clinical Psychologist; requires Completion of a Doctoral degree from an accredited University or professional school, 1900 hours of internship, and passing state exam.
Social Work	Completion of a M.S.W. from an accredited program Or equivalent, based on the State of Hawaii Department of Personnel Services specifications. No state license required. See copy.

Special Education	Completion of a Masters degree in Special Education from an accredited program or equivalent, based on the State of Hawaii Department of Personnel Services specifications. No state license required.
Speech Language Pathology	State license; requires certification by the American Speech Hearing Association (ASHA) which requires Master's degree from an accredited program, passing national exam, and completion of internship.

Because of the shortage of personnel who meet the above standards and the Difficulty of recruiting personnel for certain remote geographical areas in Hawaii, there will be an option for emergency hire of individuals who do not currently meet these standards but who will work under close supervision until either they meet the Standards or until others are recruited who meet the personnel standards developed for the State of Hawaii.

### ***Professional and Paraprofessional Standards***

Hawaii has adopted the early intervention cross-disciplinary competencies Developed by the HEICC's Personnel Committee, which served to support and guide the development of standards. However, the committee deferred responsibility to the various professional organization's leadership to develop discipline specific competencies. The following standards have been established at the professional and paraprofessional levels. Each standard below refers to "demonstrating skills for the birth-to-three age population" that each discipline determines to be important.

#### ***Professional Standards***

Professional personnel will meet the standards consistent with any State approved or recognized certification, licensure/degree requirements for their discipline, and be able to demonstrate the skills for the birth-to-three age population that each discipline determines as important.

Professional personnel will provide evidence of basic knowledge, skills, and attitudes in specified competencies that relate to services for eligible infants, toddlers, and their families.

Professional personnel will be encouraged to complete a minimum number of inservice/continuing education hours yearly related to the specific competencies. The number will be negotiated between the employer and employee upon initial hire and yearly evaluation.



### ***Paraprofessional - Assistant Level Standards***

Assistant level paraprofessional personnel will meet the minimum certification, licensure/degree requirements recognized by their discipline's professional organization or a state-recognized training program, and be able to demonstrate the skills for infants and toddlers that each discipline determines as important.

Assistant level paraprofessional personnel will provide evidence of, or have the potential to gain, basic knowledge, skills, and attitudes in specified competencies that relate to services for eligible infants and toddlers and their families.

Assistant level paraprofessional personnel will be encouraged to complete a minimum number of inservice/continuing education hours years related to the specific competencies which are expected to be demonstrated under supervision. The number will be negotiated between the employer and employee upon initial hire and yearly evaluation.

### ***Paraprofessional - Aide Level Standards***

Aide level paraprofessional personnel will have a minimum of a high school diploma. Aide level paraprofessional personnel will provide evidence of, or have the potential to gain, basic knowledge, skills, and attitudes in specified competencies that relate to services for eligible infants, toddlers, and their families.

Aide level paraprofessional personnel will be encouraged to complete a minimum number of inservice/continuing education hours yearly related to the specific competencies which are expected to be demonstrated under supervision. The number will be negotiated between the employer and employee upon initial hire and yearly evaluation.

### ***Procedures and Timeline to Meet Hawaii's Personnel Standards***

The following procedures have been developed to support individuals who currently do not meet state standards.

1. All staff will be surveyed every December 1, in conjunction with the federal data survey, to identify any individuals who do not meet state standards by discipline.

2. An individualized training plan will be developed for any individual identified by the survey who does not meet the standards.
3. Any staff shortage categories will be identified through the December 1, federal data survey. A plan will be developed to provide training to appropriate candidates to alleviate the shortage.
4. All early intervention staff will meet Hawaii's state standards, by discipline, by January 1, 2002.

The Personnel Committee has developed policies and procedures regarding notification of public and private agencies of the steps the State took to retrain or hire personnel to meet the requirements in the State. Information regarding the state standards and the requirement for all employees to be retrained to meet these standards has been disseminated to all employees and agencies.

Information concerning personnel standards for the State of Hawaii are maintained by the Department of Health. They are available for review by any interested person at any time.

## ***COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT***

The Department of Health for the State of Hawaii, on advice of the Hawaii Early Intervention Coordinating Council, has elected to develop a Part C (34 CFR 303.360) Comprehensive System of Personnel Development. This plan is founded on the following philosophical beliefs:

- Everyone currently serving this population is needed and will be urged to remain in the field.
- Everyone currently serving this population will be provided additional preparation to meet the goal of quality services.
- Parents are important members of service delivery teams.
- Parents are important participants in personnel preparation efforts.
- All personnel working with the target population should have opportunities to advance on a career ladder.
- Personnel preparation must utilize all existing resources, including institutions of higher education and in-service delivery systems.
- Employer commitment to training is needed in the form of employer incentives.
- Attitudes are as important as knowledge and skills for personnel serving the target population.

### ***Plan for Comprehensive System of Personnel Development***

1. ***Annual Needs Assessment.*** In order to insure that personnel who provide early intervention services under Part C are appropriately and adequately prepared/trained, an annual needs assessment designed to reflect both early intervention cross-disciplinary needs as well as discipline specific needs are conducted at early intervention programs. This assessment will provide information on both group and individual staff training needs. Individual training needs are identified during each staff member's yearly evaluation. Programs are also expected to assess the families they serve to identify any training needs they might have. Following the completion of these assessments, each program will have developed a list of training needs by program, by individual staff members, and by families.

2. ***Personnel Training Plans.*** Each early intervention staff member is expected to have a Personnel Training Plan in their personnel file which identifies both cross-disciplinary as well as discipline specific training needs. Implementation strategies for meeting the training needs identified on the plan are developed collaboratively between the staff member and his/her supervisor. The plan is then reviewed during the subsequent yearly staff evaluation.
3. ***Strategies to Implement Plan.*** Current efforts are underway to expand CSPD pre-service, in-service, and continuing education training opportunities to meet ongoing training needs of early intervention parents, professionals and paraprofessionals. The Personnel Committee recommends that pre-service and in-service training which is designed to address early intervention personnel needs include:
  - a. Content which emphasizes acquisition of knowledge and skills suggested in the cross-disciplinary early intervention competency goal statements;
  - b. An emphasis on skill development in the areas of family-centered, community-based care;
  - c. Current best practice knowledge and skill;
  - d. Interdisciplinary approaches to issues and practices;
  - e. Availability and accessibility of training for staff during the year at convenient times and locations;
  - f. Incentives such as certificates of completion, etc., for paraprofessionals to promote continued training on an identified career path;
  - g. Competency-based training experiences to assure that all "trainees" demonstrate performance integrating new knowledge and skills; and
  - h. Learning objectives, and training session evaluations regarding presentation content and format.

Resources to fund training activities will come from a variety of sources, including: federal funds (e.g., Part C, other grants specifically funded for personnel training activities), state funds allocated for personnel training activities; and, public and private agency funds earmarked for training activities that will increase the skills of their personnel in working with early intervention populations. A number of opportunities are being utilized in the State of Hawaii to ensure that personnel are prepared to meet the cross-disciplinary competencies.

## **Assurances**

The Department of Health for the State of Hawaii makes the following assurances regarding the personnel development system:

1. That the Comprehensive System of Personnel Development provides for the following:
  - a. Information on the training of paraprofessionals;
  - b. Pre-service and in-service training to be conducted on an interdisciplinary basis, to the extent appropriate; and
  - c. The system will provide for the training of a variety of personnel needed to provide early intervention services, including public and private providers, primary referral sources, paraprofessionals, and persons who will serve as care coordinators, as well as parents.
2. That the training provided will be consistent with the CSPD and will relate specifically to:
  - a. Meeting the interrelated psychosocial, health, developmental, and educational needs of eligible infants and toddlers;
  - b. Assisting families in enhancing the development of their infants and toddlers, and in participating in the development and implementation of the IFSPs;
  - c. Understanding the basic components of early intervention services in the state; and
  - d. Include the following:
    - 1) Implementing innovative strategies and activities for the recruitment and retention of early intervention service providers;
    - 2) Promoting the preparation of early intervention providers who are fully and appropriately qualified to provide early intervention services; and
    - 3) Working in rural and inner city areas for infants and toddlers from an early intervention program under Part C to a pre-school program under Section 619 of Part B or to other appropriate pre-school services.

## **PROCEDURAL SAFEGUARDS**

The Department of Health for the State of Hawaii is responsible for establishing or adopting procedural safeguards that meet the requirements of the Federal regulations for Part C of P.L. 105-17. The Department is also responsible for ensuring effective implementation of the safeguards by each public agency in Hawaii that is involved in the provision of early intervention services.

The Department of Health ensures the effective implementation of these safeguards by public agencies through development of the safeguards with community input provided by the various committees established by the Hawaii Early Intervention Coordinating Council. These safeguards are then reviewed and approved by the Executive Committee of the Council, and then the full Council in regularly scheduled open meetings. These safeguards will be referenced in all interagency agreements.

**Brochure.** These safeguards have been outlined for families in a brochure entitled "dear family", a copy of which is included on the following page. A copy of this brochure is given to each family at the time of intake, upon the signing of the consent form for services. The intent behind this brochure is to make procedural safeguards as understandable and "family-friendly" as possible.

**Definitions.** Relative to procedural safeguards, the following definitions will apply:

1. **Consent** means that:
  - a. The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent's native language or other mode of communication;
  - b. The parent understands and agrees in writing to the carrying out of the activity for which consent is sought, and the consent describes that activity and lists the records (if any) that will be released and to whom; and
  - c. The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time; and
  - d. The parent has the right to determine whether the infant or toddler or other family members will accept or decline an early intervention service under Part C without jeopardizing other early intervention services under Part C.
2. **Native Language** when used with reference to persons of limited English proficiency, means the language or mode of communication normally used by the parent of an eligible infant or toddler.
3. **Personally identifiable** means that information includes:
  - a. The name of the infant or toddler, their family, or other family member;

- b. The address of the infant or toddler or their family;
- c. A personal identifier, such as the infant's, toddler's, or parent's social security number; or
- d. A list of personal characteristics or information that would make it possible to identify the infant or toddler or family with reasonable certainty.

**Parental Refusal of Consent.** When a parent refuses to provide consent for release of personally identifiable information, the Department may petition the family court for appropriate relief.

**Parental Refusal of Consent for Initial Evaluation/Assessment.** When a parent refuses to provide consent for the initial evaluation or assessment, yet the referral information providing documentation that an evaluation or assessment would be in the best interest of the child, the Department may utilize impartial due process procedures.

**Opportunity to Examine Records.** In accordance with the confidentiality procedures in the regulations under Part B of the EHA Act (CFR §300.560 through §300.576 [included in the Appendix]) the parents of an infant or toddler eligible under this part will be afforded the opportunity to inspect and review records relating to evaluations and assessments, eligibility determination, development and implementation of IFSPs, individual complaints dealing with the child, and any other area regarding the provision of early intervention services for the infant or toddler and family.

**Prior Notice in Native Language.** Written prior notice will be given the parents of an eligible infant or toddler before a public agency or service provider proposes or refuses, to initiate or change the identification, evaluation, or placement of the infant or toddler, or the provision of appropriate early intervention services to the infant or toddler and family.

This consent notice will be in sufficient detail to inform the parents about the following:

- 1. The action that is being proposed or refused;
- 2. The reasons for taking the action; and
- 3. All procedural safeguards that are available under Part C of P.L. 105-17.

This consent notice will be provided in the native language of the family unless it is clearly not feasible to do so. The notice will be written in language understandable to the general public. If the native language or other mode of communication of the parent is not a written language, the public agency, or designated service provider will take steps to ensure the following:

- 1. The notice is translated orally or by other means to the parent in the parent's native language or other mode of communication;
- 2. The parent understands the notice; and
- 3. There is written evidence that these requirements have been met.

If a parent is deaf or blind, or has no written language, the mode of communication must be that normally used by the parent (such as sign language, braille or oral communication).

**Parent Consent.** Written parental consent will be obtained before the initial evaluation and assessment of the infant or toddler, as well as prior to the initiation of any early intervention services for the first time. A copy of the consent form used by the Department is included in the Appendix. If the family does not give consent for services for an infant or toddler who has been referred for services, the Department of Health will make reasonable efforts to ensure that the parent fully understands the following:

1. The nature of the evaluation and assessment or the services that would be available; and
2. That the infant or toddler will not be able to receive the evaluation and assessment or services unless or until consent is given.

**Surrogate Parents.** The Department of Health for the State of Hawaii ensures that the rights of eligible infants or toddlers are protected if no parent can be identified; the public agency, after reasonable efforts, cannot discover the whereabouts of a parent; or the infant or toddler is a ward of the State of Hawaii. The Department of Health has developed guidelines for the assignment of a surrogate parent. These guidelines include the assignment of a surrogate parent whenever one of the following conditions apply:

1. No parent can be identified;
2. The whereabouts of a parent cannot be discovered, after reasonable efforts; or
3. The child is a ward of the State of Hawaii.

All care coordinators and programs providing early intervention services have been informed of the foregoing criteria which requires the assignment of a surrogate parent. Included in the Appendix is a copy of the form used to request assignment of a surrogate parent.

A contractual relationship has been developed with the same vendor that provides surrogate parent services for the Department of Education under Part B to provide for the assignment of a trained surrogate parent under Part C whenever necessary. All surrogates used by the contractor have received training in the importance of early intervention, the types of services that may be available, and in understanding Part C regulations. This agency then assigns a trained surrogate, who lives on the same island as the child.

The Department ensures the assignment of an individual to act as a surrogate parent. The Department has established a procedure for determining whether an infant or toddler needs a surrogate parent, and if so, then assigning a surrogate parent to the infant or toddler. The Department ensures that the person selected as a surrogate parent is characterized by the following:

1. Has no interest that conflicts with the interests of the infant or toddler he or she represents;
2. Has knowledge and skills that ensure adequate representation of the infant or toddler; and
3. Is not an employee of any agency involved in the provision of early



intervention or other services to the infant or toddler.

However, a person who is qualified to serve as a surrogate parent, will not be considered an employee of a public agency solely because he or she is paid by a public agency to serve as a surrogate parent.

***Responsibilities.*** A surrogate parent may represent the infant or toddler in all matters related to the following:

1. The evaluation and assessment of the infant or toddler;
2. The development and implementation of the infant or toddler's IFSPs, including annual evaluations and periodic reviews;
3. The ongoing provision of early intervention services to the infant or toddler; and
4. Any other rights established under Part C of P.L 105-17.

***Administrative Resolution of Individual Child Complaints.*** The Department of Health for the State of Hawaii has developed written procedures under the Part C impartial procedures for the resolution of individual child complaints by parents and will provide parents a means of filing a complaint. These procedures will include:

Impartial Hearing Person. An impartial person will be appointed to implement the complaint resolution process who has knowledge about the provisions of Part C, the needs and the services available for eligible infants and toddlers and their families. This person will perform the following duties:

1. Listen to the presentation of relevant viewpoints about the complaint, examine all information relevant to the issues, and seek to reach a timely resolution of the complaint; and
2. Provide a record of the proceedings, including a written decision.

To be selected as an "impartial" person, the individual cannot be an employee of any agency or program involved in the provision of early intervention services or care of the infant or toddler. Neither can the person have a personal or professional interest that would conflict with his or her objectivity in conducting the hearing. However the impartial hearing person will not be considered to be a paid employee of the public agency, merely by being paid by the public agency to implement the complaint resolution process.

***Parent Rights at Hearings.*** The Department of Health for the State of Hawaii ensures that parents involved in an impartial hearing are afforded the following rights:

1. To be accompanied and advised by counsel and by individuals with special knowledge or training with respect to early intervention services for infants or toddlers;
2. To present evidence, and confront, cross examine, and compel the attendance of witnesses;
3. To prohibit the introduction of any evidence at the proceeding that has not been disclosed to the parent at least five days before the proceeding;
4. To obtain a written or electronic verbatim transcription of the proceeding;
5. To obtain written findings of fact and decisions; and
6. To be provided an opportunity to respond to the findings.

***Convenience of Hearings.*** The Department of Health ensures that any proceeding for implementing the complaint resolution process will be carried out at a time and place that is reasonably convenient for the parents.

***Timelines for Hearings.*** The Department of Health ensures that each complaint will be completed and a written decision mailed to each of the parties within 30 days after the receipt of the parent's complaint.

***Civil Action.*** Any party aggrieved by the findings and any decision regarding an administrative complaint has the right to bring a civil action in State or Federal court.

***Infant or Toddler's Status During Hearings.*** During the pendency of any proceeding involving a complaint under Part C, unless the public agency and parents of the infant or toddler otherwise agree, the infant or toddler will continue to receive the appropriate early intervention services currently being provided. If the complaint involves the initiation of services, the infant or toddler must receive those services that are not in dispute.

***Mediation.*** The Department of Health has developed a mediation process that parents will be encouraged to utilize prior to the initiation of the complaint procedures. A special brochure to make parents aware of the availability of mediation has been developed and is included on the following page. This brochure is given to parents at the same time as the procedural safeguard brochure, upon the signing of the initial consent form.

However, no parent will be required to use the mediation process. Mediation will not be used to deny or delay a parent's rights under the complaint procedures. The complaint must be resolved within the 30 day time period.

***Confidentiality of Information.*** The Department of Health for the State of Hawaii has adopted policies and procedures that it will follow in order to ensure the

protection of any personally identifiable information collected or used, or maintained under Procedural Safeguards. These policies and procedures are from Part B and meet the requirements of 300.560-.576 with the following modifications:

1. Reference to "State Education Agency (SEA)" means lead agency.
2. Reference to "education of (all) handicapped children" or "provision of free appropriate public education to all handicapped children" means provision of services to eligible child/families.
3. Reference to "Local Education Agencies (LEAs)" and "intermediate education units" means local providers.
4. Reference to 300.128 (Identification, Location, and Evaluation of Handicapped Children) means 303.164 and .321 (Comprehensive Child Find System.)
5. Reference to 300.129 (Confidentiality of Personally Identifiable Information) means 303.460 (Confidentiality of Information.)

***Enforcement.*** The Department of Health as the lead agency has policies and procedures in place for enforcement should any program not adhere to the regulations concerning confidentiality of information. These policies and procedures are delineated in the following section on Supervision and Monitoring of Programs.

## ***SUPERVISION AND MONITORING OF PROGRAMS***

The Department of Health for the State of Hawaii is responsible for the general administration, supervision, and monitoring of programs and activities providing early intervention services under Part C , regardless of whether or not the programs or activities are receiving assistance under Part C, to ensure compliance with the Part C Regulations.

The Department has adopted proper methods of administering each program, which will include the following:

1. Monitoring of agencies, institutions, and organizations receiving assistance under this part;
2. Enforcement of any obligations imposed on those agencies under Part C and these regulations;
3. Providing technical assistance, if necessary, to those agencies, institutions, and organizations; and
4. Correction of identified deficiencies.

Monitoring procedures have been developed for early intervention programs in the state which review both process and quality of services. The intent of the department is to encourage the adoption of "best practices" throughout the early intervention system. Monitoring is conducted annually.

In previous years, a team of three persons has been assembled to provide the monitoring of programs. These three consist of the Assistant Project Coordinator for Zero-to-Three Services Section, a parent (who is also a member of the HEICC), and a representative from an institution of higher education (who is also a member of the HEICC). The same team was used throughout the year to assure consistency of monitoring across programs. A method of assessing parent satisfaction within each program was also completed.

The results of the monitoring are reviewed statewide as a method of needs assessment to determine what other types of training and resources need to be made available to programs to assure quality of services throughout the state. This is a collaborative effort, with programs participating in a self-assessment process.

Because of reduced resources, the most recent monitoring (FY 1997) consisted of an examination of records to determine whether the program met federal regulations and timelines. Both these monitoring methods consisted primarily of process indicators and did not examine the impact of services of the child and family.

***Service Testing.*** Service testing has been introduced to Hawaii as a method of monitoring by the Felix Technical Assistance Panel. It has been used statewide to examine how the system of care is functioning and how it is improving over time. Service testing is outcomes focused. It is a review process used to find out to what extent children with special needs and their families are benefitting from services

received and how well the local service system is working for those children and families. Each child served is a unique "test" of the system.

The Zero-To-Three Services Section, with the approval of the Hawaii Early Intervention Coordinating Council (HEICC), determined that this monitoring method offered significant potential advantages over previous monitoring methods. Therefore, this method is being used on a pilot basis this year. The original protocol, developed primarily for school age children with behavioral challenges, was modified, in collaboration with the authors, to be utilized in early intervention settings.

Service testing results are quantifiable on a range of 1-6 for both the child, family and the service system. An undesirable performance for either falls in the ranking from 1-3, with a desirable performance falling between 4-6. The protocol provides specific criteria to apply in making the judgment about the performance in each area. Attached is a more thorough description of service testing methodology and interpretation of results.

After training and orientation for both the reviewers and the program staff, six cases are selected at random to represent a composite of the services provided by the program. Each program is being service tested by a team of three: a community or HEICC member, a parent, and a Zero-To-Three Services Section representative. Each team member is responsible for an intensive, in-depth examination of the services and collaboration surrounding two families. Following the completion of the process, the results will be shared with the program and with the families participating in the process.

**Sanctions.** Should the monitoring process identify areas in which programs are not in compliance with the Hawaii Part C Early Intervention State Plan, including the applicable Federal regulations (including all procedural safeguards), sanctions may be applied to that program. This could include the withholding of contractual payments pending the development of internal policies to rectify the deficiencies. Technical assistance will be provided by the state to assist in resolving the deficiencies.

## ***LEAD AGENCY PROCEDURES FOR RESOLVING COMPLAINTS***

The Department of Health for the State of Hawaii has adopted written procedures for receiving and resolving any complaint that one or more requirements of Part C are not being met. It will conduct an independent on-site investigation of a complaint whenever it determines that an on-site investigation is necessary.

An individual or organization may file a written signed complaint with the Department which contains the following information:

1. A statement that the State has violated a requirement of Part C of P.L. 105-17 or the Regulations of P.L. 105-17; and
2. The facts on which the complaint is based.

Within 60 days of the receipt of a complaint, the Department will carry out an independent on-site investigation, if necessary to resolve the complaint. In exceptional circumstances, an extension of this time line may be made in respect to a particular complaint. The Department reserves the right to request the U.S. Secretary of Education to review its final decision.

The Department of Health assures that there are procedures to ensure that services are provided to eligible infants and toddlers and their families in a timely manner, pending the resolution of disputes among public agencies or service providers. The complete description of these procedures are written in the section entitled "Interagency Agreements & Resolutions of Disputes."

## ***POLICIES & PROCEDURES RELATED TO FINANCIAL MATTERS***

1. The Department of Health for the State of Hawaii assures the following:

- a. HDOH has a description that ensures resources are made available under this part for all geographic areas within the State. (20 U.S.C. 1437(a)(7));
- b. HDOH has a policy pertaining to contracting or making of other arrangements with service providers to provide early intervention services in the State, consistent with the provisions of Part C, including the contents of the application used and the conditions of the contract or other arrangements. (20 U.S.C. 1435(a)(11));
- c. HDOH has a procedure for securing timely reimbursements of funds used under this part in accordance with 20 U.S.C. 1440(a). (20 U.S.C. 1435(a)(12));
- d. HDOH ensures identification and coordination of all available resources within the State from Federal, State, local and private sources. (20 U.S.C. 1435(a)(10)(B)). These include, but are not limited to Title V of the Social Security Act (relating to Maternal and Child Health); Title XIX of the Social Security Act (relating to the general Medicaid Program and EPSDT; The Head Start Act; Parts B and C of the IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the Elementary and Secondary Education Act of 1965, as amended; and the Developmental Disabled Assistance and Bill of Rights Act (P.L. 94-103). It is also responsible for maintaining accurate, current information on these funding sources, if a legislative or policy change is made under any of these sources.
- e. Fees will not be charged for services that an infant or toddler is otherwise required to receive at no cost including:
  - 1) Child Find;
  - 2) Evaluation and assessment;
  - 3) Service coordination;
  - 4) Administrative and coordinative activities related to the development, review and evaluation of IFSP; and
  - 5) Implementation of procedural safeguards.
- f. The inability of the parents of an eligible infant or toddler to pay for services will not result in the denial of services to the infant or toddler or to their family;
- g. All mandated services, as specified in P.L. 108-446, will be provided at no cost to all parents of infants and toddlers with special needs from birth to age three;
- h. A sliding fee scale will not be utilized for mandated Part C services.

2. Anticipated funding sources for early intervention services include, but are not limited to:
  - a. State general fund;
  - b. Federal funds under P.L. 108-446;
  - c. Medicaid;
  - d. Private insurance;
  - e. Special Federal/State grants;
  - f. Local county funds;
  - g. Private agency support;
  - h. Early Intervention Special Fund and Trust Fund.
3. Use of Public and Private Insurance – The Department will make every reasonable effort to collect payments under Medicaid, Champus (TriCare), and private insurance in accordance with the following guidelines:
  - a. Parents will be asked to provide consent when required under 34 CFR §§303.401, 303.404, 303.360 and 300.571, in order for the Part C lead agency to make requisite disclosures of personally identifiable information and access public and/or private insurance. Refusal of a parent to provide consent will not result in the denial of any service under Part C.
  - b. HDOH participating agencies, private providers and subcontractors will be required to ensure that parental consent has been obtained prior to accessing public or private insurance for any mandated Part C service.
  - c. The Department will not require parents to use insurance proceeds to pay for mandated Part C services if the family would incur a financial cost. Financial cost includes:
    - 1) A decrease in available lifetime coverage or any other benefit under an insurance policy; or
    - 2) An increase in premiums or the discontinuation of the policy.
  - d. The Department will ensure that if private insurance is accessed, families will not be charged directly for co-payments, deductibles, and/or registration fees. The Department reserves the right to pay for co-payments, deductibles, and/or registration fees to ensure there is no financial cost to the family.
  - e. The Department may request parents file a claim for reimbursement when costs are incurred (e.g., registration fees).
  - f. The Department, in ensuring payment for early intervention services, in no way relieves an insurer or similar third party from an otherwise valid obligation to provide or to pay for early intervention services for an eligible infant or toddler.



4. Dispute Resolution – The Department has developed the following procedures to ensure that services are provided to eligible infants and toddlers with special needs and their families in a timely manner, pending the resolution of disputes among public agencies or service providers.
  - a. Pending the resolution of the dispute, the Department will utilize Part C funds to directly pay for the services;
  - b. At the request of the Department, the Hawaii Early Intervention Coordinating Council will conduct a Public Hearing amount the agencies and parties involved in the dispute, then assign the responsibility to the appropriate agency;
  - c. Upon resolution of the dispute and assignment to the appropriate agency, the Department will invoice the appropriate responsible agency for the reimbursement of Part C funds.

## ***INTERAGENCY AGREEMENTS & RESOLUTIONS OF DISPUTES***

There were existing interagency agreements between the Department and the Department of Education and the Department of Human Services that were executed prior to the passage of P.L. 99-457. There has been no need to execute specific interagency agreements, because in Hawaii, the Department of Health pays for all early intervention services, except for those covered under a third party source of payment. Those payments are made directly rather than through a reimbursement process.

There are numerous purchase-of-service contracts with private agencies for the provision of early intervention services. The following is a description of the current status of agreements with both public and private agencies.

### ***Public Agencies***

***Department of Human Services (DHS).*** The DHS has obtained approval from HCFA Region IX to add targeted case management for infants and toddlers with special needs to its eligible services. This was implemented beginning in 1994. This agreement is included in the Appendix. It continues to be in effect for children eligible for Supplemental Security Income. In addition, effective August 1, 1997, DHS entered into an agreement with the Department for a carve-out of early intervention services under the 1115 statewide QUEST waiver. This MOA is also in the Appendix. Recently an MOA was developed to provide access to Title IV-E funding for specified training activities.

***Department of Education.*** It is not anticipated that there will be any financial responsibility on the part of the Department of Education for early intervention services, including any use of Part B funds. The Department of Education is represented on the Council by the head of the Office of Special Education. This has provided a way of facilitating interagency collaboration without an interagency agreement.

This has included cross-agency representation on committees and task forces developing each other's state plans. It has also included collaboration for public awareness and child find activities. The Department also participated in the Child Count under P.L. 89-313 and it received approval from the Department of Education for its proposal for the utilization of the funds generated by the count of infants and toddlers.

The Department of Health has negotiated an agreement with the Department of Education on a number of issues specific to Part C. A copy of that agreement is included in the Appendix.

## ***Private Agencies***

The Department currently has a multitude of agreements with private agencies for the provision of early intervention services. These agreements include those funded by state appropriations, as well as those funded under Federal grants, including P.L. 105-17. Copies of samples of those agreements are included in the Appendix.

## ***Components of Agreements***

Should new interagency agreements be necessary, when they are negotiated, will contain the following components:

1. The financial responsibility of each agency;
2. Procedures for resolving disputes; and
3. Additional components to ensure effective cooperation and coordination.

## ***Resolution of Disputes***

The Department is responsible for resolving individual disputes, in accordance with the procedures in §303.523 of the Part C regulations, using the following procedures:

1. For the period during which the dispute is being resolved, the Department shall pay for the services, using Part C funds, as the payor of last resort;
2. Upon resolution of the dispute and assignment to the appropriate agency, the Department shall invoice the assigned agency for the reimbursement of Part C funds or will make payment to the appropriate agency, if expenditures have been incurred by the agency originally assigned financial responsibility.
3. As may be necessary to ensure compliance with the assignment of financial responsibility, the Department will refer the dispute to the Governor.

## ***POLICY FOR CONTRACTING FOR SERVICES***

The Department of Health for the State of Hawaii has established a policy for contracting or making other arrangements with public or private providers of early intervention services.

1. All early intervention services provided will meet the State standards and be delivered in a manner consistent with the Part C Regulations.
2. The Department shall contract for services under a Request for Proposal (RFP) process utilizing the Hawaii Revised Statutes (HRS) Chapter 103F requirements of the State of Hawaii for contracting for services. A copy of HRS Chapter 103F is included in the Appendix.
3. These individuals or organizations being contracted for services must meet the HRS Chapter 103F requirements as well as agree to provide services consistent with Part C regulations.
4. A sample contract, negotiated with private agencies, providing early intervention services, as previously described, is included in the Appendix.

## ***DATA COLLECTION***

The Department of Health for the State of Hawaii has established a data collection system for early intervention services to assist it in planning for services and personnel, for the tracking of services to eligible infants and toddlers and their families, for the monitoring of the implementation of the Individual Family Support Plans, for the timely submission of required reports, for the management, administration and monitoring of programs, and for the evaluation of early intervention services within the State. The data will be reported to the U.S. Secretary of Education as required under §.676(b)(14) as well as other information required by the Secretary.

### ***Data Systems***

***HEITS.*** The Hawaii Early Intervention Tracking System (HEITS) is an automated information management system designed for use by agencies involved in the implementation of Part C. This microcomputer-based information system enables detailed program information to be gathered locally and aggregated centrally to meet state and federal planning and reporting needs.

HEITS is currently being used by 16 early intervention programs throughout the state to support the data collection, tracking, and reporting needs of each local program. Data for children and families including intake information, health, and developmental status, care coordination, IFSPs, referrals, and service provision is recorded by the program responsible for providing care coordination. With the consent of parents, information is shared with other programs serving the child and family, transferred between programs when care coordination changes, and uploaded monthly to the central database at the Zero-to-Three Services Section to provide unduplicated reporting of all families in early intervention programs throughout the state.

Families referred to the early intervention system are linked with appropriate services through the Central Point of Contact, and these referrals are documented in HEITS. This centralized system of "registering" children and their families receiving early intervention services prevents duplication of services between programs, and tracks children who otherwise might be lost to services.

HEITS provides complete information for all eligible children due to developmental delays. It also includes a portion of the population eligible because of environmental risk.

**NURYS.** HEITS was modified to create an information tracking system for public health nurses (NURYS). They use this system to track all the children between birth and age three for whom they are providing care coordination services as well as for all clients served by public health nurses. This system is directly linked to HEITS so that data can be directly uploaded.

**Other Data Systems.** There are a number of other data systems operated by agencies serving environmentally at-risk infants and toddlers. These include the Healthy Start Program and Kamehameha Schools Preschool Programs. Unfortunately these systems are not directly linked with H-KISS; therefore, these programs utilize their data systems submit the required data on a hard-copy format.

### ***Data To Be Collected***

1. The following types of data will be collected from each program:
  - a. Numbers of infants and toddlers served;
  - b. Types of services provided;
  - c. Personnel providing services;
  - d. Expenditures for services;
  - e. Sources of funding;
  - f. Service delivery sites;
  - g. Additional personnel needed; and
  - h. Training needs of existing personnel.
2. The information gathered from this data collection effort is used by the Department and HEICC in continuing planning and evaluation efforts, as well as to fulfill reporting requirements.

In addition to the data systems, additional data is submitted on monthly and quarterly reports by agencies providing services under a purchase of service (POS) contract. A copy of the reporting form is included in the Appendix.